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LOYOLA UNIVERSITY CHICAGO

THE PICTURE OF HEALTH:

A CASE STUDY OF THE USE OF ALTERNATIVE THERAPIES AND THE  
CREATION OF COMMUNITY BY PEOPLE LIVING WITH HIV AND AIDS

A THESIS SUBMITTED TO  
THE FACULTY OF THE GRADUATE SCHOOL  
IN CANDIDACY FOR THE DEGREE OF  
MASTER OF ARTS

DEPARTMENT OF SOCIOLOGY

BY

LORRAINE ANNE LYNN

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## ACKNOWLEDGEMENTS

I wish to thank everyone at the Chinese Medicine HIV Center (CMHC). I am especially grateful to MHL, an acupuncture practitioner, who brought me into the interviews with clients and explained theories of TCM so that a sociologist might understand what was happening. I am also grateful to MR who helped me maintain my "balance" when I was not to sure I would be able to. Finally, I am eternally grateful to the clients of CMHC who allowed me to ask very personal questions about their lives and health.

## DEDICATION

To Edde who I hope will share in many future projects  
and to Greg K. who passed away before this one was  
completed.

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## CHAPTER 1

### INTRODUCTION

Ideas of health and sickness seem to be understood as fairly straight forward and distinct categories in our society. If someone is the picture of health the underlying assumption is that the individual is "well." In sociology, Talcott Parsons influenced these ideas of health and illness through the concept of the "sick role." Parsons' sick role is enacted when a person experiences the temporary limitations of illness. It exempts an individual from his or her daily responsibilities until that person gets well. Even with the expansion of the "sick role" to include individuals with chronic disorders, patient responsibilities and obligations follow the pattern of an "acute" illness (Fox 1989).

However, some types of ill health do not fit the acute illness model. Conditions which are defined as "chronic" leave little hope for the individual to recover and escape the sick role (Charmaz 1991). Other types of illness become attached to an individual by a "diagnosis" of a virus. This virus may take years to manifest into symptoms which would keep a person from carrying out his or her societal responsibilities. For many individuals living with HIV and AIDS, it is this experience of illness by diagnosis that

influences not only the definition of self, but the actions of their everyday lives.

The research in this thesis examines how a specific group of men living with a diagnosis of HIV or AIDS challenge the images as well as the notions of health and illness attached to the idea of the sick role. By engaging in a process of health care that puts them into a position to question the dichotomous relationship of healthy and sick these men are engaged in redefining the meaning of health. By negotiating the boundaries between conventional Western medicine and alternative therapies they gain access to the knowledge and perspectives of both healing systems they develop health strategies that support the body and fight the disease.

The use of alternative therapies<sup>1</sup> as a strategy for health care is a common but often unrecognized phenomenon. In the United States, studies show that one-third of the population uses alternative therapies at an annual cost of fourteen billion dollars (Eisenberg et al. 1993). In Chicago, prevalence of this phenomenon can be seen through free public magazines like the bimonthly Conscious Choice Resource Guide. Such resources provide listings of

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<sup>1</sup>I use the phrase alternative therapies to mean the variety of healing systems, including Traditional Chinese Medicine, that operate outside of the conventional allopathic western medical system. I chose "alternative therapies" because it is the phrase the participants of this study used most often to describe these other healing systems.



practitioners of alternative therapies around the region. The 1995 April/May Guide included fifty-eight practitioners or therapists.

Despite this apparent popularity, alternative therapies in general have had difficulty finding a legitimate place within the boundaries of the conventional Western system of medicine. Historically there has been an expectation among researchers and practitioners of Western medicine "that folk and popular systems of health beliefs and practices would inevitably decline in modern and industrialized societies, falling away before the forces of modernization and progress to be replaced by modern, Western medicine (O'Conner, 1995, 1)."

However, research has consistently shown this expectation to be unfounded. As O'Conner explains:

Nonbiomedical healing systems have persisted steadily alongside the burgeoning medical establishment...In the past two decades especially, there has been a significant reinvigoration and expansion of nonconventional healing systems of all sorts (1).

Though much of the continued use of alternative therapies has been linked with various immigrant communities there is also an expansion in usage of alternative therapies among mainstream<sup>2</sup> health care consumers. One prominent reason that alternative healing systems are used by health care consumers is that Western medicine has not been able to

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<sup>2</sup>O'Conner (1995) defines "mainstream" patient populations as patients who are members of the dominant cultural groups in the United States.

provide solutions to many of society's chronic health problems (Lauerman, 1993). However, rather than abandoning Western medicine, many patients of alternative therapies choose to include both health systems as different strategies for health care.

O'Conner argues that urban, middle-class, gay men, with HIV or AIDS are at the forefront of this movement of including alternative therapies among their health strategies (1995). In examining the use of alternative therapies by people with HIV and AIDS in the Philadelphia area, researchers found that forty percent of the patients using conventional Western medicine also incorporated alternative medicine into their treatment regimen (Anderson et al. 1993).

Observers might suggest that the use of alternative therapies by people with HIV and AIDS is a reaction of desperate people facing a fatal prognosis. But for the majority of the gay men whose lives will be revealed throughout this thesis, the decision to include and continue to use alternative therapies reveals a much more complex collection of personal, social, and physical reasons. These men are engaged in a process of seeking options in treatments and support which help them to challenge the social and physical stigma of AIDS. They work to question the label of the sick role by redefining its exemption and responsibilities. Rather than presenting themselves as

sick, many of these men are the picture of health in both their physical presence and an outlook that challenges the social context and biological expectations of the diagnosis of HIV or AIDS. This exploratory research begins to examine how these men engage in this process of redefining the meaning of health.

In the Chicago area there are several organizations providing access to alternative therapies for people with HIV and AIDS. This thesis is a study of one of these organizations. Drawn from ethnographic data collected for a project examining the effectiveness of treatments and organization, I provide a portrayal of the men who make this organization a part of their lives, examine why they go to this organization and what keeps them coming back, and finally explore the influence of the organization itself.

## CHAPTER 2

### LITERATURE REVIEW

Ideas and expectations of health in the United States are understood predominately through a traditional Western scientific perspective of the body. This perspective is based within a system of science and medicine which contains not only beliefs and practices that define health but that work to define the social relations of healing. O'Conner argues that practices and values which underlay them make up the institution of Western medicine which then maintains its official status backed by social, economic, and political power of society (1995, 4). As the official institution or system of health, Western medicine maintains the authoritative voice in defining health, wellness, sickness, and treatment. It has become the taken for granted perspective on wellness and health.

Though the dominant voice in defining health and the activities of healing, the system of Western medicine has not been immune to challenges. Like many of society's institutions, the system of medicine found itself caught up in the rising currents of social change in the 1960s and 1970s. Many groups of people, both within and outside of the established institutional systems, took action to

challenge traditionally accepted and unquestioned beliefs and practices (Imber 1991, Evans 1979). Janiger and Goldberg characterize the institution of medicine within this context of social change:

[T]he theoretical model on which modern medicine had been erected was being seriously challenged, and the impulse to question prevailing wisdom was compounded by social forces. In keeping with the spirit of the times, segments of the population realized that medicine was as imperfect as other institutions. Along with authority figures from schoolteachers to presidents, doctors found their pedestals shaking from beneath their feet. Medicine was faulted for becoming depersonalized, a charge stemming from spiraling costs, reliance on technology at the expense of the human touch, bureaucracies made necessary by hospital-based treatment and third-party reimbursement, the sudden preponderance of specialists, and the near extinction of the wise, caring family doctor who knew his patients intimately and attended them from cradle to grave (1993, 27).

Such concerns opened the door for challenges to accepted notions about the autonomy of doctors and the privileged position of Western medicine, from both within and outside of the medical establishment (Imber 1991). Challenges pushed the boundaries creating space for discussion and for negotiating new social relations of healing.

Groups of health workers, including doctors, as well as patients were frustrated with a medical system that did not seem interested in "care" but only to dispense advice and medication. Janiger and Goldberg examined cases of physicians, in residency and in practice, who found themselves questioning the dominance of their own Western medical knowledge of health care. Some became frustrated and migrated to other countries to search out and learn

different ways of healing. Others adapted their practices by including knowledge and experience with alternative healing forms (Kaptchuk 1983, Janiger and Goldberg 1993). Still others directly challenged the relationship between practitioners and clients by providing a more patient-centered, holistic practice (Lowenberg 1989, Wolpe 1990). Lowenberg suggests that physicians, because they are members of the medical system, pose the most immediate threat to the authority of Western medicine when they challenge accepted practices (1989).

External challenges from outside the medical system resulted in the creation of new types of medical practice which included both structural changes and introduction of Eastern and Holistic forms of medicine<sup>3</sup>. The challenge to medical authority led by clients of medical practice, revolved around questioning the right of professionals to make decisions about individual lives based solely on professional expertise (Haug and Sussman 1969, Friedson 1970, Friedson 1986). Challengers insisted that professionals should make their diagnoses and prognoses on treatments with input from the patient and with a

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<sup>3</sup>Lumping all other healing systems into one category, alternative medicine has many problems and implications (See O'Conner, 1995). The most obvious is that being juxtaposed to Western medicine puts all other forms of medicine and healing into the role of the Other, thus reenforcing their defined illegitimacy. An important aspect of my research is to show that the variety of alternative forms of medicine/healing are legitimate because those who use them have experienced them to be.

consideration for the patient's social situation which then gives a context to the illness (Dychtwald 1986).

The Free Clinic Movement of the 1960s and 1970s provides an example of the intersection of these challenging forces. By attempting to create structures and practices different than those of the medical establishment groups of people from inside and outside of the system of medicine challenged the authority of western medicine. According to Case and Taylor (1979), free clinics grew out of anti-war demonstrations of the 1960s and early 1970s. People protested as part of a political action would often find themselves in violent situations as the authorities would squelch these acts of civil disobedience. Violence which occurred in many demonstrations left injured protestors, who often did not have the benefit of medical insurance, with no place to go for medical treatment. So clinics were created within organizations or communities to handle this medical crisis. Soon these clinics found themselves dealing with other health issues of transient, poor, urban populations. Operated by volunteers, medical paraprofessionals, students, ministers, and members of the community these clinics found themselves struggling to continue their existence.

Free Clinics or Community Clinics brought medical services to populations in need by creating an structure alternative to the conventional medical system. But they found that abandoning the social relations of this system

difficult, if not on occasion impossible. These relations are not only embedded in the beliefs and practices of everyday medicine but also within the production of medical knowledge including the nature of disease, treatment, and cures. Although seen by those originally involved as an alternative to the established system of medicine to better answer the health care crises within urban areas they soon discovered advantages to working with the established system.

The 1980s saw another type of crisis in health and care which has fueled another round of "alternative" ideas about health. The history of the AIDS epidemic in the United States is laden with stories of mis-information and denial which often lead to the expansion of the disease and many times to death (Shilts 1987). Though clearly not the only population devastated by this epidemic, the white gay middle-class community was best positioned structurally to take action and challenge the knowledge and actions taken by the government, science, and medicine. According to O'Conner the gay men most able to be involved in these challenges were and continue to be well-educated professional men, concentrated in urban settings, who were accustomed to autonomy in all aspects of life. Many who had gained political training during the earlier Gay Rights movement were motivated to take social and political action on their own behalf (Epstein 1991, O'Conner 1995).



Unlike previous movements which challenged the authority of the system of medicine the AIDS movement in the United States questioned the production of scientific knowledge about the disease providing a "relentless critique of, and intervention within, the institutions of science and medicine (Epstein 1991, 36)." Unique to this movement is that participants are positioned to challenge institutions from a variety of levels. In defining the United States AIDS movement as one which challenges the authority of scientific knowledge Epstein explains:

These activists wrangle with scientists on issues of truth and method. They seek not only to reform science by exerting pressure from the outside, but also to perform science by locating themselves on the inside (1991, 37)."

By being inside the institutions, those loyal to the movement could question both the procedures and the knowledge produced. According to Epstein, members of the U.S. AIDS movement were in a position where they could challenge medicine and science from both outside and within as the result of being able to convert "disease 'victims' into activist-experts (Epstein 38)." Skeptical of established authority and having the social skills, professional connections, and economic position to successfully challenge scientific knowledge led many members of the white gay middle-class to influence epidemiological interpretations of AIDS causation and to conduct underground drug trails and run underground pharmacies

(Abrams 1990).

Yet, as with those people involved in the Free Clinic movement, people with HIV involved with the United States AIDS movement, retain their reliance on the establishment of Western medicine. But they are not limited in the therapies which they can incorporate into their strategies for staying healthy with HIV and living with AIDS. As O'Conner shows urban, middle-class, gay men with HIV or AIDS are at the forefront of a movement to include alternative therapies as a legitimate form of health care (1995).

The variety of alternative medicines and forms of healing which have existed throughout the history of the United States have predominately operated unofficially outside the system of Western medicine (Gevitz 1988, O'Conner 1995). The recent rise of interest in alternative therapies by mainstream patients reflects the concerns and perspectives of social change and health care during 1960s and 1970s. From the perspective of the client practitioner provided alternative therapies offer a more holistic relationship of treatment by maintaining the idea that client and practitioner are working together toward a healthier client. Typically, alternative therapies are undertaken by patients to address those conditions which Western medicine is not able to effectively treat. The challenge of medical authority which began in the 1960s created a space for alternative practices, structures, and

systems of healing into the 1990s.

Today the limited effectiveness of Western medicine in treatment of chronic health problems often leads patients to explore other forms of healing. When relief is not available through conventional medicine then those who are suffering may turn to other avenues of treatment (Lauerman 1993). Another perspective on the use of alternative therapies places them not as "alternatives" to Western medicine but as complimentary therapies. The use of a variety of healing systems reveals the complexity of health care strategies individuals undertake to address health problems. O'Conner explains:

When used concurrently, the different systems to which an individual has recourse may be selected because each is believed to deal well with specific features of the health problem....This type of usage reflects a common characteristic of vernacular health belief systems, many of which view conventional medicine as addressing only symptoms or treating proximate causes of sickness, while the vernacular system is equipped to deal with critical ultimate causes (1995, 27)."

This conception of different health systems being used in conjunction to address different aspects of a health problem was the dominant perspective expressed by the men I interviewed at the Chinese Medicine HIV Center (CMHC) as I discuss in later sections of this thesis.

The prevalence of use of alternative therapies as part of an overall health care strategy is estimated at around one-third of the United States adult population (Eisenberg et al. 1993). The demographic characteristics of the group

surveyed revealed that contrary to accepted beliefs of medical researchers, mainstream health consumers are using alternative therapies. According to the study, people who use alternatives are predominately white (82%) persons between 25 and 49 years of age (50%) with relatively high education levels, (40% with or above college level education). They also found that the majority of these people used alternatives for chronic illness rather than life-threatening, medical conditions.

Of those individuals who used alternatives seventy-two percent did not tell their Western medical doctors. Yet among individuals who used alternatives for serious medical conditions they also sought treatment for the same condition from medical doctors. O'Conner explains that for individuals who find few options from conventional medicine, they look to alternative therapies<sup>4</sup> to expand those options:

Sicknesses that do not respond well to conventional Medical care, or for which few conventional treatment options exist, frequently motivate people to develop purposive self-care routines and to explore a range of forms of potential treatment. Serious illness with poor prognoses may especially quickly lead people to expand their health care strategies beyond the bounds of conventional medicine, in an effort to multiply their therapeutic options....As a devastating disease with a poor long-term prognosis, and often with minimal response to a medical armamentarium that is still quite limited, HIV/AIDS is exemplary of the kind of health crisis that promotes the widest possible range of vernacular treatment responses (1995, 109).

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<sup>4</sup>O'Conner (1995) does not use the phrase, alternative therapies. Instead she uses Vernacular Health Belief Systems to mean the variety of alternatives to the Conventional Health Belief System.

The findings of Anderson et al., support O'Conner's contention that when Western medical treatment options are limited individuals will seek to multiply their options. The researchers surveyed predominately gay men receiving Western medical treatment at three hospital-affiliated Philadelphia HIV outpatient facilities in order to determine the extent of use of alternative therapies by people with HIV or AIDS. This study found that forty percent of the HIV-positive patients incorporated alternative therapies into their treatment regimen (Anderson et al. 1993). It would seem, that within the some areas of the organized gay community, alternative therapies are legitimate options for some form of treatment of HIV or AIDS as they work in compliment to limited conventional medicine.

Along with the physical relief patients seek by including different therapies, Western medicine and alternative therapies offer differing philosophical perspectives when addressing health problems. Conventional Western medicine has as it mission, "curing" through the elimination or at least reduction of sickness while alternative therapies emphasize supporting the health of the person by "healing" the underlying imbalances. As O'Conner explains:

Curing generally refers to the removal or correction of organic pathology. Healing can encompass such matters as comfort, care, family and community relationships, quality of life, peace of mind, restoration of dignity, acceptance, spiritual growth, even ultimate salvation (1995, 28).

However as Aakster points out the types of therapy and the comfort they provide though different are not mutually exclusive. He contends that if disease is interpreted as an imbalance "vitalizing and destructive forces (268)" then Western medicine works to "destroy, or at least suppress, the demolishing or sickening forces (268)" while alternative medicines "strengthen the vitalizing forces (268)."

Yet Western medicine remains the dominant voice in defining health and diagnosing illness in society. Adam (1992) contends that the power of the diagnosis of HIV or AIDS often overwhelms an individual's identity by assigning to him or her an identity constructed from the perspective of authorities. Weitz points out from her interviews with people with HIV, a diagnosis of HIV or AIDS has both biological and social aspects. In biological terms one *becomes* a person with HIV when that person is diagnosed as infected with HIV. In sociological terms not only does one become infected but must "recognize this change and reevaluate him - or herself accordingly (1991, 52)." The "social context" of the HIV or AIDS requires people with the virus to live as individuals with this illness as well as to live in society defined by the stigma of that illness.

Weitz's work, which draws on data collected in two urban areas in Arizona in the 1980s, emphasizes the isolation and despair individuals with HIV or AIDS

experience through negative interactions with family, neighbors, colleagues, and health care workers including physicians. Her focus is on the social stigma attached to AIDS and how that impacts individuals living their lives.

Weitz's ground breaking qualitative study made apparent the effects of stigma on the lives of individuals facing HIV or AIDS (1991). Weitz clearly shows the powerful influence of authoritative definitions of "deviance" and "health" in the voices of people with HIV or AIDS interviewed. Kleinman also vividly describes the effect of the voices of authority on the process of identity formation for individuals experiencing illness:

Each statement encases the patient in a visible exoskeleton of powerfully peculiar meanings that the patient must deal with, as must those of us who are around the patient. These meanings include the fear of lingering and untimely death, the threat of disfiguring treatment with the concomitant loss of body- and self-image, the stigma of self-earned illness, discrimination against homosexuals, and so forth. That exoskeleton is the carapace of culturally marked illness, a dominant societal symbol that, once applied to a person, spoils radically that individual's identity and is not easily removed (1988, 22).

My research is a case study of a clinic providing alternative therapies to people impacted by HIV or AIDS. Though the focus of the research is to understand how this group of people creates meanings of health and wellness. Similar issues that Weitz addressed in terms of stigma did come up in discussions and interviews. The focus of my research however always revolved around the question of how spending time at CMHC related to those social issues.

Social issues which at their base were problematic because of a diagnosis with HIV or AIDS.

For the clients I interviewed at CMHC, facing the long-term prognosis of dying from a debilitating disease, the use of alternative therapies is undertaken and maintained to stay healthy. They are used to build up the "immune system" helping it to fight off an opportunistic infection for as long as possible. Western medicine meanwhile offers protection against specific infections. Alternative therapies are supportive, while Western medicine has the arsenal.

The imagery of the body as a system of balance that alternative therapies provide, play out in the every day image that the men that I observed and talked with projected. For the most part, these men looked healthy. In conjunction with the research I would carry out for CMHC, I became interested in how these clients created and maintained this image of being healthy. Along with that, I wanted to explore if they saw themselves and acted in their relations within CMHC as healthy individuals.

Finally, I contend that the process of seeking out and using alternative therapies can provide people with HIV or AIDS with knowledge and experiences with health to challenge both the biological and social aspects of illness. As Weitz points out for people living with HIV:

Regardless of what choices individuals make...the ability to make choices helps individuals feel in



control of their lives and thus helps make life with HIV disease seem worth living (1991, 101).

My research from CMHC explores how a specific group of men who are living with HIV or AIDS negotiate the borders of alternative therapies and Western medicine and how they draw from the knowledge of both to create new meanings of health. The social space within CMHC also influences this process by providing opportunities for individuals to challenge the stigma of AIDS and redefine the picture of health.

## CHAPTER 3

### THE CHINESE MEDICINE HIV CENTER

#### The Research Site

The Chinese Medicine HIV Center (CMHC) is a small alternative clinic on the Northside of Chicago. It is one of many community based organizations located in the landmark Uptown Bank building. This majestic building houses the Uptown Bank and nine floors of office space which the building management company leases to a variety of organizations and businesses. The community area of Uptown has historically been a port of entry for the many migrants and immigrants who enter Chicago (Bennett, 1991). The occupants of the Uptown Bank building reflect the diversity of this community. Sharing the fifth floor with CMHC is an Asian-Indian domestic violence advocate organization, two bilingual dentist offices (one Spanish and one Asian-Indian), a Caribbean-African business organization, an immigrant health education project, and a Spanish speaking dental supply business.

The Uptown Bank is a prime location for organizations and businesses because of its location to public transportation. Major East to West and North to South Chicago Transit Authority bus routes stop right in front of

the building's west doors and one half block to the east is an elevated train stop. CMHC is located on the east side of the building so the "el" rumbles past every ten minutes or so. This access to public transportation is used by some of CMHC's clients and practitioners who do not have access to a car.

Exiting the elevator to the fifth floor a smokey sweet smell blends with the musty odor of the old building. Follow the aroma and you find the source is CMHC. Inside the office space the combination of burning sandalwood incense and moxa, made of mugwort, permeates both your senses and clothes. Clinic lore has many stories revolving around this smokey smell which resembles the scent of burning marijuana. Once familiar with the aroma I could tell whether CMHC was open by its intensity upon exiting the elevator.

The people who have contact with CMHC call it a clinic. The first time I entered the space, in July of 1994, it had little resemblance to the understood physical structure of a medical clinic. The front room was large and open. It had a few scattered chairs, a water cooler, a table with magazines, pamphlets, and newsletters all with the themes of HIV, AIDS, and/or alternative therapies. Beside the table was a desk where a young woman sat reading a book. She gave me a warm greeting when I entered. I explained that I was there to see Arthur, the clinic director, and she went to

the back of the office to tell him. As she walked across the room I noticed that she wore no white smock or brightly colored flowered dress, the attire which I associated with clinics. Instead she dressed in basic urban attire, black shirt, tights, and shoes. She returned with the message that he would be right out and she sat back behind the desk and resumed her reading.

I sat on the yellow vinyl couch, with a crocheted, blue afghan draped across it and listened to the music playing in the background. Not the typical office muzak, this music had distinctively Asian tones. Though I noticed these things, the worn yellow couch, the music, the woman at the reception desk, I did not fully understand the role each played in creating CMHC. I expected that these things were meant to make a person entering the clinic feel comfortable and relaxed, but I would find that many of the physical, personal, and sensual aspects of the clinic were intricate to the understanding of CMHC as an organization.

Shortly, Arthur, the clinic director, emerged through the doorway from the back of the clinic. He was dressed casually in a polo shirt, shorts, and sandals. He lead me back into what appeared to be a spacious office, containing a large desk with a chair on either side, then he talked eagerly about the chance to do a research project at CMHC. The organization had submitted a grant proposal to the

Policy Research Action Group (PRAG)<sup>5</sup>, at Loyola University of Chicago. He implied that they were looking for funding, and were surprised when they ended up getting a research assistant. Still, Arthur had many ideas for research projects to carry out under the broad purpose outlined in the PRAG application discussed later in this chapter.

He briefly explained the mission of CMHC including the view of the role Traditional Chinese Medicine plays as a treatment for HIV and AIDS. Then he took me on a tour of CMHC. The fifth floor suite which houses CMHC is basically a rectangular box divided into a series of smaller rectangular and square boxes. From the more spacious office where we had our initial discussion Arthur lead me down the hallway past two other "office type" rooms. Next to the more spacious executive directors office is the staff office. It holds a desk, three chairs, a four drawer filing cabinet containing patient files, files from a past research project, and other assorted files. Message boxes for acupuncturists are stacked on the corner of the desk. Also sitting on the desk was the "Clinic Log." Arthur explained that the practitioners used this log to communicate with

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<sup>5</sup>PRAG provides support for community based organizations (CBOs) to develop a collaborative relationship with academic institutions and personnel. PRAG helps CBOs develop research projects that will help CBOs in accomplishing their mission; helps identify academic faculty interested in the same subjects; provides research assistants and small grants to CBOs to work on a project (Excerpt from mission statement enclosed with request for funding application, March 1995).

each other and that he would write about my coming to CMHC in there. He said I could also use this log for communicating with the other practitioners, but I would find later on that the most effective way to talk with anyone at CMHC was face-to-face, any other method of communication brought confusion and sometimes suspicions about the research I would eventually carry out.

Alongside the staff room is a small room with a round table and several chairs. Although I'm sure he told me what the room was for it would not be until much later in the research process that I would understand the purpose of this little room. One acupuncturist would eventually label it the intake room, though most clients and practitioners would call it by the description of the events that take place there. As one client aptly called it, "the little room where they take your pulse." I will use the label "intake room" for brevity.

At the end of the hallway was an open room which Arthur called the large treatment room distinguishing it from the smaller treatment room which was attached to the intake room. The large treatment room had three massage tables lined up next to each other. Against the outside walls were several chairs, plants, a small chest of drawers, and a clothes hamper. On the walls were four red hazardous materials boxes, two charts one showing the acupuncture points on the human body and the other highlighting the

acupuncture points on the human ear, and a white message board with a list of items under the title "Wish List." Two large windows provide a view toward Lake Michigan and the rumbling elevated trains.

Arthur explained as we stood in this large open room that clients were treated here rather than in separate treatment rooms. The term "treatment", I would come to understand referred to acupuncture. He stressed that the treatments were provided in this forum to avoid isolation of the client and to encourage clients to talk with each other about treatments. The smaller treatment room held two more massage tables. The small treatment room has doors which close providing privacy. The main purpose for this private room Arthur explained was for providing a treatment space for women. As I became more familiar with CMHC I would learn that there was a noticeable lack of women clients to utilize this smaller room. More often, this room is considered the massage room. This room contains two tables, the massage oils, and the futon mattress used for Shiatsu massage.

Before I left, Arthur gave me a copy of his recently published book, Treating AIDS with Chinese Medicine, which he co-authored with Mary Kay Ryan, the other founding practitioner of CMHC (1994). Drawing from this book and conversations within the clinic it is clear that the history of CMHC as an organization is linked directly with the rise

of the AIDS epidemic. In the mid 1980s, Chicago was beginning to experience the upward progression of AIDS cases among gay men, which had already had devastating effects in San Francisco and New York (Shilts 1987). Treatments for AIDS were not yet apparent and AZT trials were in their beginning stages. Abrams (1990) suggests that the "frustration and despair" experienced by the gay male community, which was devastated by this disease, lead to the development of an alternative therapies movement. Self-prescribed treatments such as mega dosing with vitamin C and the creation of "guerilla pharmacies" for producing herbal and chemical compounds emerged within the gay community. O'Conner (1995) explains that along with creating underground access to more conventional therapies came the incorporation of alternative therapies<sup>6</sup> including Chinese medicine, macrobiotic diet, massage, meditation, and a variety of other therapies located outside of the conventional western medical system.

In Chicago, in 1986, five practitioners representing both Western and Eastern<sup>7</sup> therapeutic traditions, combined

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<sup>6</sup>O'Conner (1995) uses the phrase "vernacular health belief systems" to refer to the wide variety of health care possibilities located outside of the conventional Western health belief system. I choose to use the phrases "alternative therapies" or "complimentary therapies" because these are the descriptive terms most often used by the clients at CMHC.

<sup>7</sup>Throughout the discussion in this chapter Eastern therapeutic or healing practices refers to the wide variety of non-Western healing systems. Traditional Chinese



their efforts founding the Alternative Health Center<sup>8</sup> (AHC) to provide therapies for people with AIDS. In their book, Ryan and Shattuck, who were also involved in the creation of AHC, explain the compelling reasons drawing this group of practitioners together:

Our personal concerns included commitment to help relieve the suffering of the gay men's community; commitment to and inspiration by Chinese-style public health; dedication to combined synergistic Western and alternative medicine; and a search for a more humanized practice of medicine (1994, 1).

Ryan and Shattuck admit that early on they were uncertain of the impact of Chinese medicine would have on people suffering with HIV and AIDS. However, they knew that Chinese medicine could treat the symptoms associated with the virus including night sweats, fevers, fatigue, and diarrhea. These were symptoms that Western medicine was not able to effectively treat. Bringing both Western and Eastern therapeutic traditions together this group of practitioners hoped to overcome the differences in perspectives and build a tradition of complimentary care.

Authors and researchers of both Western and Chinese medical traditions agree that each differs from the other in their philosophy, terminology, diagnostic techniques, and logic of understanding and treating illness. Kaptchuk

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medicine (TCM) is one non-Western tradition. Use of the term, alternative therapies, which comes from people within CMHC also refers to non-Western therapeutic or healing practices including TCM.

<sup>8</sup>The Alternative Health Center is a pseudonym.

explains that the difference in logic between the two systems of understanding has sent these traditions in opposite directions. Western medicine, according to Kaptchuk, operates like a microscope, tightening the focus until the specific cause is identified. He explains:

Western medicine is concerned with isolable disease categories or agents of disease, which it zeros in on, isolates, and tries to change, control, or destroy. The Western physician starts with a symptom, then searches for the underlying mechanism -- a precise cause for a specific disease (1983, 4-5).

Chinese medicine, Kaptchuk explains, practices with a much broader focus. A practitioner of Chinese medicine does not exclude specific causes from the diagnosis. Instead he or she includes this specific agent as part of a full spectrum of interacting factors. Kaptchuk describes this "holistic" perspective:

The Chinese physician, in contrast, directs his or her attention to the complete physiological and psychological individual. All relevant information, including the symptom as well as the patient's other general characteristics, is gathered and woven together until it forms what Chinese medicine calls a 'pattern of disharmony.' This pattern of disharmony describes a situation of 'imbalance' in a patient's body. Oriental diagnostic technique does not turn up a specific disease entity or a precise cause, but renders an almost poetic, yet workable, description of a whole person (1983, 5).

In theory bridging these differences and combining these traditions makes sense for providing complete care for patients. In Double Vision (1994), Todd examines alternative therapies including the introduction of a macrobiotic diet as successfully contributing to fighting cancer. Todd followed the experience of her son who endured

surgery and high dosage radiation to eliminate a rare form of cancerous tumor which had grown behind his eye. Acupuncture and visual imagery meditation contributed to his recovery by keeping his body strong and calming his anxieties while Western medicine attacked the pathogen. Ryan and Shattuck, also explain how Eastern and Western healing therapies can work together, "TCM and especially acupuncture can sometimes provide very rapid relief of debilitating symptoms, often letting the patient feel better while the Western medicine and Chinese herbs are working at the root cause (1994, 40)." However, the reality of cooperative care was more difficult to accomplish. Differences in perspectives coupled with an ignorance about these diverse healing traditions made it difficult for practitioners to develop a cooperative team approach to care. Ryan and Shattuck suggest that practitioners, "undermined each other's treatment by countermanding prescriptions and giving patients incorrect information about each other's modalities (1994, 6)."

For Shattuck and Ryan, the solution to this problem was to create a clinic that provided focused treatments. In 1990 they opened the Chinese Medicine HIV Center. Rather than offer a wide variety of alternative therapies, CMHC concentrated on providing only acupuncture, herbal therapy, and massage. These treatments remain the core of CMHC as an organization with 97% of clients surveyed listing

acupuncture as a purpose for visiting CMHC (Appendix A).

Conversations with Arthur and many of the people who came to CMHC after it opened revealed another reason for opening a second alternative clinic, access to treatments. According to many of the clients, CMHC has a flexible policy on making appointments when compared to another alternative health center located in Chicago. One former client of this clinic commented:

Clients can only make appointments a week in advance. Regular clients can call in beginning Monday to make appointments for the following week. Those on the waiting list can then begin to make appointments beginning Wednesday. They keep close track of people who miss appointments. And if you miss a certain amount you get bumped from the regular list to the waiting list. It took me six months to move off the waiting list (Field Notes, February 6, 1995).

By opening CMHC Arthur explained during several conversations, they were expanding the opportunities for people with HIV or AIDS to receive treatment without having to wait. CMHC further simplified access to treatments by providing therapies to anyone who showed up at their door regardless of their ability to pay.

This flexibility in providing client care is reflected in the two guiding principles of Shattuck and Ryan developed for founding CMHC. First the physical structure of the clinic was based on an open Chinese-style clinic where clients receive acupuncture treatments in the group setting of a common treatment room. The set-up encourages client interaction in an effort to reduce the feeling of isolation.

Acupuncture is the main form of treatment at CMHC providing the base of the treatment package.

The second guiding principle applied to the cost of treatments. CMHC initially operated as a donation only clinic and clients were asked to donate to the clinic however they could. Donations could be made through working, providing office equipment and furniture, and less frequently by giving money to the clinic. As will be discussed in a later chapter, this method of donation proved useful for drawing people into the responsibilities of running the clinic. However, it has also contributed to financial problems for CMHC. Faced with limited access to outside funding, CMHC shifted from a perspective of donations to memberships. Since its opening in 1990 CMHC has gone from no charge, to twenty dollars per month, to sixty-five dollars per month, to finally eighty-five dollars for a monthly treatment package. The impact of these price changes will be explored later in this thesis. However, it clearly the overall price changes effected the social relations within CMHC as they contributed to the changing nature of the relationship between clients and the organization.

### Therapies and Practitioners

Traditional Chinese medicine (TCM) has many therapies which a practitioner may incorporate into a treatment. Acupuncture, herbal medicine, and massage are three TCM

therapies used at CMHC. Acupuncture is based on the assumption that the body is made up of meridians which transport energy called Qi. Along these meridians there are points which can be manipulated in various ways; with needles, heat, finger pressure, and scraping, to maintain the energy balance (Kaptchuk 1983, Aakster 1986, Ryan and Shattuck 1994). At CMHC manipulation is predominately done through needling acupuncture points. Heat may be used in combination with the needles by burning moxa the fragrant herb which gives CMHC its distinctive aroma. The moxa is burned near a point or on the needle itself. This treatment process lasts between twenty to forty minutes. According to the practitioners the duration and type of the treatment depends on the determined strength of the individual client.

In Chinese medicine, herbal formulas are used along with these other therapies to address some aspect of imbalance within the body. Herbs are prescribed by the practitioner in formulas of a number of substances to address an underlying cause of disharmony, to treat an acute condition, or to build or strengthen a system (Ryan and Shattuck 1994). The practitioners at CMHC prescribe many types of herbal formulations that are produced by the Institute for Traditional Medicine (ITM) in Portland, Oregon. Because of a special agreement between the Executive Director of ITM and Arthur, CMHC gets these formulas for less than wholesale cost. They then provide

the ITM formulas to their clients at wholesale cost saving clients 100% on the retail price. For example, Composition A, an herbal formula which is prescribed to enhance or strengthen the immune system costs \$25.00 for a bottle of 420 tablets at CMHC. The cost for an equivalent amount is \$50.00 at a health food store frequented by CMHC's clients. Chinese patent formulas, produced in China, are also frequently prescribed. They are very inexpensive, \$2.50 for two hundred "BB" sized tablets, and can be purchased locally in Uptown at one of many Vietnamese markets or pharmacies.

Massage, either Swedish or Shiatsu (Japanese form of acupressure), is a popular form of complimentary therapy among clients at CMHC. Therapeutically, in Chinese medicine, massage is seen as manually stimulating the points on the meridians and affecting the muscle and tissue of the body (Ryan and Shattuck 1994). As I would learn from clients, although the manipulation of muscle and tissue is appreciated, massage is also emotionally therapeutic by providing safe, caring touch.

The various forms of therapy are carried out by CMHC's staff of health care practitioners. Composed of licensed acupuncturists, acupuncture interns, and massage therapists these practitioners work predominately as volunteers for one shift each of the days CMHC is open. The acupuncturist acts as "coordinator" of clinic activities on their shift. From my conversations with them and observation, their

responsibilities include opening and setting up the clinic, diagnosing and treating clients, coordinating and training volunteers and interns, and knowing the answers to any and all questions about CMHC, alternative therapies, and other resources available for people affected by HIV or AIDS. For this work they are promised a small stipend, around three hundred dollars each month. This is a very modest stipend as acupuncture practitioners are able to make that amount or more a day in private practice. The continuous financial problems that plague CMHC makes the reality of a stipend a rare occurrence. Instead acupuncturists, like all other staff, end up working as volunteers. For these practitioners, the dedication to providing relief for clients and the need to "pay the rent" create a conflict for which there is no good resolution.

As mentioned earlier one of the responsibilities of the acupuncture practitioner is the coordination and training of interns. CMHC provides experiences for training both acupuncture interns and massage therapists. Two regional training schools are the main suppliers of interns and massage therapists. The Midwest School of Oriental Medicine, headquartered in Madison, Wisconsin, is the Midwest region's only training school for Chinese medicine. Both the interns and the practitioners at CMHC share the common history of this school. The trials and tribulations of dealing with the school's administration act as a bond



between interns and acupuncturists. Interns must have three hundred hours of supervised clinical training to satisfy a portion of their degree requirements. These hours must be include experience with a variety of health conditions so most interns put in time as volunteers at several clinics.

Massage therapists are also drawn from the Chicago School of Massage Therapy. As part of their training, these massage students must work 100 hours in clinical settings as well as volunteer a specific amount of hours. Massage is a labor intensive form of therapy so each volunteer is limited to three sessions.

Both the supply of interns and massage therapists at the clinic vary continually. Because both groups are usually still completing their course work, their availability is linked to the requirements of each new school semester. From the perspective of the organization, acupuncture interns are fundamental to the clinic as a source of possible replacements and to provide access to new knowledge for practitioners. In fact the loss of three acupuncture practitioners from February through June of 1995 was buffered by having a reserve of capably trained and certified acupuncturists who having done the majority of their intern hours at CMHC and who were familiar with the clients and operating procedures of the clinic.

#### The Board of Directors

All official policies and procedures concerning the

operation of CMHC are decided by the Board of Directors. The Board, as it is called by clients and practitioners, meets formally once each month to address issues surrounding the operation of CMHC. Board members include CMHC clients, practitioners, and community members. The president of the Board is also the executive director of CMHC. He is responsible for the administration of the Board's decisions as well as the daily management of CMHC. He is also the only person at CMHC who has a contract stipulating payment of a salary. Nevertheless, the precarious funding of CMHC forced him to work as a consultant on a city transportation project in order to earn a living for the summer of 1995.

I would find throughout my research that among many clients and practitioners the make-up and purpose of the Board of Directors was and remains ambiguous. Both clients and practitioners interpret the responsibility of the Board as two-fold. The Board is responsible for creating organizational policies and for bringing the necessary monies to enact these policies. Many of the clients and practitioners expressed concern that little action was being taken by the Board to keep the doors to CMHC open. Yet, CMHC continued to remain open and both acupuncturists and clients continued to show up.

### Clients

When I first met with Arthur he boasted that CMHC had a client base around two hundred. From surveys and

observations it appears that there is a consistent number of between twenty to thirty clients who visit CMHC each week. Other clients visit intermittently, sometimes because of changing work schedules, sometimes because of illnesses. When a practitioner leaves, which happened fairly frequently during the course of this research, the client group he or she has built up typically drops off, although some eventually do return. Occasionally a new client will come to the clinic having heard about CMHC through a rare article in a gay magazine or through a reference from a case worker, therapist, or resource organization like Test Positive Aware. Most people who become clients at CMHC however, find out about it through friends.

The clients of CMHC are predominately gay, white, middle-aged, well educated, males who have been diagnosed HIV positive (For percentage breakdown see Appendix I). All of these descriptive terms present a picture of this group of clients that makes them appear similar. However they are not a unified group. Using the term "gay" can be misleading in that it may be assumed that "gayness" is an all encompassing identity. It should be understood that gay males are as diverse in their everyday selves as are all people. O'Conner's explanation of the gay community reveals the complexity of communities of identity,

Its size, distribution, and diversity sustain several well-defined subcultural groups, as well as microculture characterized by generally shared bodies of tradition, custom, lore, and language, and a clear and articulated

sense of group identity among members (1995, 110).

What O'Conner describes as the organized gay community seems similar to the gay men who visit CMHC. She explains that they are for the most part, "professional men with well-developed problem-solving skills, accustomed to a good measure of autonomy, strongly motivated to take social and political action on their own behalf, and having excellent social and historical reasons for being skeptical of established authority (1995, 110)."

Within CMHC there is no difference between clients and members. The term "client" was used by practitioners and people receiving treatments at CMHC. The term "member" is the official name attached to the payment process. The term client implies that CMHC provides a service for people. According to the understood contract, the people receiving the service then "pay" for that service in some way. The term member implies a different type of relationship between the receiver of the service and the provider. Member suggests belonging to the organization and having some sort of responsibility for that organization. However, clients are more than mere recipients of treatments at CMHC, they are participants in the social world of CMHC. In many ways, the clients shape the social and structural aspects of CMHC.

### The Research Process

As a research assistant from the Policy Research Action Group (PRAG) CMHC was to be the third community-based

organization I would do research for. By definition I was to assist CMHC in carrying out their proposed project using a collaborative model. The collaborative model, as defined by Nyden and Wiewel is a process for research that gives members of community-based organizations the power to participate and influence all stages of the research process. Nyden and Wiewel explain,

This is research where all parties, "researcher" and "client" are equal partners. There is equal participation in defining the research problem and the research strategies. It is recognized that the research[er] may have certain technical expertise and the community leader may have knowledge of community needs and perspectives. Rather than either side using these resources to gain control in a research relationship, they need to be combined to provide a more unitary approach to research (1992, 45).

The project was guided by the broadly defined purpose in the "Project Proposal Form" submitted to PRAG in the Spring of 1994. Drawing from this proposal, the purpose of research at CMHC was, to document and analyze the effects and efficacy of various treatments being offered by CMHC, with the goal of improving client care and enlarging the body of knowledge about how herb therapy, acupuncture and massage are able to contribute to the quality of life of people impacted by HIV.

Early in the research process Arthur and I worked together to define the project, to determine the methods and to decide the objectives and eventual outcomes of the study. In order to bring a focus to what information Arthur wanted to gain from this research I often asked him to explain what

he wanted to know about CMHC. He responded,

What's working here? What is it that clients are getting from CMHC? What's the treatment? What are the components of the treatments? Is it the acupuncture, massage, herbal therapy that relieves symptoms or are is that just a part of it? What is the most overriding symptom, something physical that is treated solely with the therapies or is it some other aspect of well-being that is treated through some other aspect of the clinic (Field notes, October 24, 1994).

I saw the design of the project as providing information about both the treatment process and daily practices at CMHC. We agreed to carry the project out in three phases, participant observation, distribution of a questionnaire, and through in-depth interviews with client members. I began observing and taking field notes beginning with my first meeting with Arthur. From early observations a survey was developed to gather basic demographic data about clients and to begin to explore client perspectives on treatments, practitioner relationships, and organizational activities. These concepts would then be explored more in depth through face-to-face interviews with selected clients in order to better understand the context of the clients experience at CMHC.

For more background information on the use of alternative therapies by people with HIV or AIDS Arthur sent me to talk with a researcher from a large AIDS organization in Chicago. As this researcher and I sat at a Tai noodle shop, he excitedly provided ideas on how to design the project and he encouraged me that the results would be of

great interest to practitioners, researchers, and people with HIV and AIDS. He introduced me to the relevant literature on Traditional Chinese Medicine (TCM), (Kaptchuk 1983, Ryan and Shattuck 1994), HIV and AIDS (Shilts 1988, Nelkin, Willis, and Parris 1991, Adam, 1992), and the patterns of use of alternative therapies (Anderson et al. 1993, Eisenberg et al. 1993, O'Conner 1995). This literature supported my beliefs that the best way to get at the perceptions of treatments, effectiveness, and quality of life was to situate myself within CMHC, and to look at the clinic from the perspective of clients.

By beginning the project with observations I was drawn into the day-to-day activities of the clinic where I was able to see the social workings of the clinic and better understand the client perspective. My field observations and conversations with practitioners, clients, volunteers, interns, massage therapists and others involved with CMHC all gave me a broad perspective of the complex relations between treatments, organization, and social interactions among people within the clinic.

Because I entered this community as a researcher, I was an outsider and neither clients nor practitioners were sure of my relationship to the clinic. At first any conversations I would begin transformed to monologues by clients and occasionally practitioners involving one of several topics including a complete analysis of the

usefulness of alternative therapies in general, on the benefits of low-cost clinics, or on the history of crises CMHC had and continued to experience. The information gathered through these early experiences guided the development of a survey for the next phase of the research project.

With guidance from Arthur, and approval from the executive director, I developed the Treatment Effectiveness Survey (Appendix B). Through this questionnaire I set out to gather information on three areas of CMHC: demographics, organizational processes, and the treatment process. Eight open-ended questions addressed aspects of the treatment process. These questions focused on practitioner client relationship, treatment effectiveness and outcomes, and client involvement with CMHC.

The staff were given instructions to hand out questionnaires to all clients who came to CMHC between the dates of November 28, 1994 to December 23, 1994. Questionnaires were given to each individual only once during this time period. Completed questionnaires were returned to CMHC in sealed envelopes. A total of 62 surveys were handed out during this time and a total of 32 (52%) were completed and returned.

The results of the survey gave me a picture of the general client make-up and brief insights into their reasons for using alternative therapies (Appendix A). The later



aspect would be the focus on the rest of the project. The open-ended questions asked clients to examine their relationships with practitioners, the effectiveness of treatments, and their involvement with CMHC. These questions provided guidance for the later client interviews exploring this use of alternative therapies by people with HIV or AIDS.

The practitioners and I chose the clients to participate in the face-to-face interviews. The most important criteria for choosing respondents was that they represented the diversity of the clients at CMHC in terms of their health and relationship to the organization. The six<sup>9</sup> informants ranged in terms of initial contact with the clinic (1 to three years) however only one had no prior experience with Traditional Chinese Medicine (TCM) or other alternative therapies<sup>10</sup>. All were white, gay, males above the age of thirty. At the time of the interviews, two were volunteers and clients, one had left the clinic, and three were simply clients. Five were diagnosed HIV positive, while one had received an AIDS diagnosis. Knowledge of HIV positive status ranged between two and eight years.

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<sup>9</sup>We originally agreed to interview ten clients but the time schedule did not allow for it. The results of this project were presented at the AIDS and Chinese Medicine conference in New York in June of 1995. To keep the data at a manageable level we reduced the interviews to six people.

<sup>10</sup>Four of the interviewees followed Arthur from AHC to CMHC. Of these four, three were not involved with alternative therapies prior to diagnosis of HIV.

Five of the six interviews were done in either the offices or the intake room at CMHC. One was done in the cafe on the first floor of the Uptown Bank building. Four of the respondents I knew before the interviews, two I did not. All gave oral consent to be interviewed and to have the interviews tape-recorded with the knowledge that the interviews would be transcribed and identifying information removed. Interviews ranged in time from forty-five minutes to over an hour. The interview guide included topic areas of overall health, life with HIV/AIDS, treatment regime, understanding and explanation of treatments, and involvement with CMHC (Appendix C).

Employing this research perspective, I was also able to examine the social relations within the clinic to understand how they influenced the daily organizational activities and the treatment processes. Beginning within the everyday social relations of CMHC and utilizing a variety of research techniques provided a wide range of data which I could draw from to understand and explain what clients meant by "treatments" and how the clients made the connections between these treatments and their own quality of life. What also emerged from the initial research was an opportunity to continue this study beyond its intended purpose and pull together all aspects of observation, survey, and interviews over time to develop a case study of this alternative treatment center.

Guiding the development of this case study were two questions that grew from the initial research project. The first question, which was actually a set of questions, revolved around the use of alternative treatments. How did these people come to use these forms of treatment? How did alternative therapies become a legitimate option? How does the understanding of HIV and AIDS change by combining therapies? While the second question came from observing the social relations of CMHC. With other similar clinics around the city why keep coming to CMHC?

The next two chapters explore these questions and many others that were defined by myself, the practitioners, and the clients about the role and influence of alternative treatments on this group of people with HIV or AIDS. What happens at CMHC revolves around the physical and social experience of being healthy. The structural conditions and social interactions within CMHC influence the redefinition of the meaning of health and wellness that many of the clients undertake. How this new meaning of health is used by clients to challenge the image and stigma of AIDS is also examined.

## CHAPTER 4

### DOING SOMETHING: SEEKING OUT OPTIONS

Several authors have noted that urban, gay, middle-class has greater access to resources relative to other populations where HIV and AIDS are concentrated (Epstein 1991, Ryan and Shattuck 1994, O'Conner 1995). In contrasting the different "communities" experiencing the AIDS epidemic Ryan and Shattuck describe the gay community as having previously established coherent and accessible structures which provided channels for outreach and education about alternative therapies:

The gay male population already has numerous community and health care organizations. It also tends to be better educated and informed relative to other HIV affected groups and therefore somewhat more open to new approaches. It is well versed in fighting for its rights and more likely to apply this political expertise to issues of health care (1994, 9).

Through networks and resources like the Gay Men's Health Crisis in New York and Test Positive Aware in Chicago, gay men facing the crises of HIV or AIDS can gain access to scientific knowledge about the disease and treatment. Also organizations like these provide information addressing the practical experiences of living with HIV and AIDS. In a survey of the clients at CMHC, thirty-one percent found out about the clinic and its

treatments through these media networks (Appendix A).

Another important resource for learning about CMHC was friends. Forty-seven percent of the clients at CMHC found their way there through friends. Though this information is useful for understanding what brought the men to CMHC it only begins to answer the question of why they would seek out alternative therapies as an option in health care. To explore why the men at CMHC begin doing something about the threat HIV makes to their health and well-being I draw on three questions; How were these people are drawn into using alternative therapies?; How did they determine alternative therapies to be a legitimate treatment option?; and How did the use of alternative therapies influence their image of living with HIV or AIDS?

One assumption that I took into the research process was that individuals who came to CMHC would be drawn to using alternative therapies because of their distrust of Western science and philosophy. To my surprise very few clients held this perspective. Instead most found themselves seeking out the options of alternative therapies as part of an overall health support system for living with HIV or AIDS.

Although there were some clients who came to CMHC because of an historical pattern of using alternative therapies they were fewer than I had expected. The men who did fit this profile expressed a personal belief system

which they saw as contrary to Western philosophy or science.

Mack<sup>11</sup> explains:

I was very heavily into metaphysical stuff, new age kinds of things and it just fell into place as being a good alternative to expensive doctors and chiropractors. I would see results much more quickly. It was a very positive experience for me, it always has been (Interview, March 6, 1995).

Another client, Jack, who despite having been HIV positive for eight years did not include Western medicine in his options for treatment, reveals that along with his beliefs he maintains a strong distrust in Western medicine in general and of the use of drugs specifically. He explains:

I'm definitely not a Western medicine person at all. For as far back as probably late high school, early college, I read health books. Books on fasting, books on vitamins, books on herbs, effective diet... [I] read a lot of things that say Western medicine, in a lot of ways, now clearly if I were in a car accident and my thigh bone were sticking out of my leg I'd go right to the hospital and have them do whatever they said needed to be done...I just have a belief that Western medicine and drugs, although there are a lot of good things that have come out of it, there's just a lot of negative things. And it tends to work against the body rather than with it...I don't do drugs at all (Interview, March 10, 1995).

Even with their early exposure to alternative therapies, clients like Mack and Jack began to expand their treatment options after their diagnosis of HIV. For many of the clients at CMHC it is the initial diagnosis of HIV, whether their own or of a friend, that encourages them to begin seeking out their treatment options. Sometimes

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<sup>11</sup>All client names are changed to maintain their anonymity.

individuals set out to find their options while others were not interested in being involved, but through the insistence of friends found themselves engaged.

Tom, a client who has been HIV positive since 1988, explained that he got involved in alternative therapies because his lover "dragged" him into it:

Paul [his lover] dragged me to one of the nights for [the alternative clinic]. Because I was not at the time, in fact until Paul died, I was not much of looking for things to do, to help my health. I wasn't quite one of those people that hands their life over to the doctor and says heal me but I also wasn't one to go out and search out things on my own and read lots of things, stuff like that (Interview, March 10, 1995).

However, after his lover Paul died, Tom found himself becoming more involved in exploring options on his own:

I'm much more aggressive and looking for things...[l]ike herbal therapies, new research, findings on medical research studies although I'm not really gung ho about taking medicines, I like to know what's out there and how its working. I'm very conservative in terms of taking new medical treatments myself. But if something looks promising and doesn't seem to have lots of negative side effects I might consider taking it. So I try to always keep open to whatever's out there cause you hope its going to work for you (Interview, March 10, 1995).

While Jeff, a client diagnosed HIV positive since 1990, found himself seeking out options as part of caring for a close friend who by the time he was diagnosed as HIV positive was already suffering from the opportunistic infections of AIDS:

And so when they both came back positive, (pause) I sort of kicked into care giving mode, I was like okay, we'll try everything, we'll look at what we can do and we started getting books, drink this tea, do this, blah, blah, blah, cause some of the western stuff was making

him sick, and he was already sick. So, and four months later he was dead. So I thought, we better get started here. I mean he hadn't had time to look at things that could maybe have benefited (Interview, April 4, 1995).

The experience of watching friends and lovers die influences clients' decisions to do something about their own health. Through the experience with death, which includes Western medical interventions, many of these men begin to question the dominant knowledge and expertise of the physicians they had come to depend on for relief from health problems. The inability of their doctors to treat the associated symptoms of HIV or the side effects of various Western drugs provides a space for clients to challenge the dominant knowledge and negotiate the influence of physicians on their health care decisions. Once again reflecting on the experience of his friend's death Jeff explains what he sees as the limitations to treatments:

[T]he procedures that western medicine takes, are very, (pause) I mean he [his friend who died] was well cared for I guess in the capacities that they have, but they're very, "This is what you have to do!"...And my doctor's that way. You know when I first suggested some alternative therapies he said, "Sure go ahead just don't waste too much money." And its like you have to do it yourself, they don't work in partnership with you anything alternative. I mean some doctors may, but mine doesn't and I know his didn't (Interview, April 4, 1995).

Such experiences question the fundamental relationship between client and expert. Faced with this dilemma many of the men at CMHC who have the option, exercise their right to find a Western health care provider who will recognize their clients' perspective that using alternative therapies is



positive for their individual health. For some this is a long process that requires the investment of a great amount of time. Tom explains how the choice to incorporate alternative therapies and avoid taking AZT led he and his lover on a search for a new physician:

We came to this doctor because our previous doctor did not accept those things, and at one point told Paul to go ahead and die if he wasn't going to take AZT, and don't come back. That led Paul to go and search out a new doctor, and he went out and interviewed a few doctors. Interviewed meaning he had the initial consultation with each one, and we chose this one because he was very compassionate and somewhat open to alternative kinds of medicine. He really evaluates it strongly from a Western medicine standpoint but he's not immediately dismissive of it. And so, he kind of watches me. And if there's something I'm considering I'll bring it to him and ask his opinion and there are questions as to efficacy or safety um, but he knows that I come here and I guess the other big thing is that, his viewpoint is that its my life and my health so its my decision what I do with my body, not his. He's just the adviser (Interview, March 10, 1995).

By being able to recognize the doctor as an advisor to his own decisions about his health Tom finds himself actively pursuing his own health care regimen. He becomes the center and from this center he reaches out choosing which options he determines as beneficial for him. Like many of the clients at CMHC, Tom, through the experience of his lover's death, is acutely aware of the limitations of Western medicine to understand and treat HIV and AIDS. By considering health care providers as advisors many of the men at CMHC are able to pursue other options like alternative therapies and self-care.

However, seeking out options does not mean abandonment

of Western medicine. With the exception of Jack, who to the time of the interview had not experienced any opportunistic infections related to his status as HIV positive, most clients maintain relationships with their medical doctors and almost all include in their options Western pharmaceuticals as either preventatives against or treatments for specific opportunistic infections associated with AIDS. When asked about his treatment regimen, Tom, like many of the clients, lists Western medications along with alternative therapies and self-care options:

I use both, but I use not as much Western medicine as probably the average person with HIV. I'm not taking any antiretroviral...it comes up every time I go to the doctor. For a while I was putting it off and then I had another reason I was doing other things and now its back to putting it off again. But I cannot see anything I want out there that I really want to be taking. I'd rather stick with the natural stuff, and know its not going to have a negative impact on my body...I have a doctors appointment about every month. The meds that I'm on are antivirals, a couple prophylaxes...the rest of my regime, that's the tiny part of my regimen, the rest of it is lots of supplements or herbs...and acidophilus, and I'm doing [a nutrition program]...And that's it, acupuncture and massage also. (Interview, March 10, 1995).

When asked, most of CMHC's clients, like Tom, can recite a weekend shopping list of both Western and alternative therapies they incorporate into their health care regimen. Many are fairly certain of the diagnostic reason for taking their Western drugs and the overall influence of those drugs on their physical health. However, when asked about the reason for using alternative therapies as part of their health care their diagnostic language

becomes limited.

Drawing on one of CMHC's concerns of how clients determine the effectiveness of treatments brings up the question of why these men continue to incorporate alternative therapies into their treatment options. With Western medicine, clients consider both the physicians recommendations and the physical effects of the medications. Physical discomfort caused by the side effects of specific drugs or combination drug therapies often lead these men to negotiate a different version of the study protocol or to quit using the medications. Jeff explains from his experience with a combination study:

I know how the western drugs make me feel, I just called with the 3TC study and AZT study and I'm like, "I won't live like this, I'm sick all the time." So they said, "well drop down to the low dose." So we're going to see how that works. And supposedly I can take something to help the nausea, or whatever the western stuff is doing (Interview, April 4, 1995).

Similar criteria are used to evaluate the effects and effectiveness of the treatments received at CMHC. Acupuncture, massage, and herbal therapy are judged both in terms of relief from specific symptoms or side effects of Western medication. These therapies also have an important quality from the client perspective of being effective for reducing stress and providing a sense of relaxation.

When describing alternative therapies in relation to symptom relief or relief from side effects of medications clients at CMHC drew on the language of Western science.

Mack, a client whose HIV positive diagnosis came in 1992 when he was diagnosed as having tuberculosis, defines the effectiveness of alternative therapies in terms of symptom relief, he also links that symptom to Western medication. Because he relies predominantly on conventional drug therapy for treatment and prevention of opportunistic infections, Mack turns to acupuncture for relief of the physical side effects of those medications:

I had, uh, I still have a little bit of it, but I had neuropathy in my feet and ankles and the acupuncture has definitely lessened that. Almost to the point that I don't have it anymore. We know that's being caused by my medications...I take AZT in combination with ddc through a study group, and we know that its the ddc that's causing the neuropathy. So they cut my dosage back in that but I still have neuropathy the acupuncture definitely has alleviated that, relieved it. (Interview, March 6, 1995).

Jack, who, as mentioned earlier, does not incorporate conventional Western medicines into his treatment regimen, discusses the effectiveness of herbal treatments for symptom relief using a scientific experimental framework:

So I came here and I started doing the herbs...And I did them for about eight weeks and then I had some big intestinal problem...so I stopped doing the herbs and within days I started noticing my energy dropping. And just cut out everything, and I think I started back with the herbs, gee maybe two months later...and within three days, I could just tell that I was feeling better. And then at some other point I stopped doing the herbs... energy went down, started them up again, energy much better. So I've been doing them pretty steadily for two and a half years...And there is no question in my mind that when I consistently stay on between three and four times a day, the herbs, that I feel much better, things just work better, and most of my symptoms...[are] much better...So, you know I've had definite improvements (Interview, March 10,

1995).

For Jack, herbs take the place of Western medications and he uses them in the same way. He also evaluates their effectiveness by measuring his own physical reactions.

Incorporating this type of evaluation method and language is possible with herbal therapies which often work for clients as alternatives to Western 'toxic' medicines. However, the language of science and medicine is more difficult to use when discussing the effectiveness of acupuncture treatments. If the treatment is related to a specific symptom then the client can provide an "legitimate" evaluation of the effectiveness of the acupuncture treatment to relieve that symptom. However, acupuncture is more often connected to relaxation and/or increasing energy. To describe these kinds of effects clients will use a combination of psychological, New Age, and Chinese medical terms. Jack describes his experiences of acupuncture as sinking into a wonderful place even though he is not sure if the treatments work on specific symptoms:

The acupuncture I've been doing regularly once a week. And the major thing I feel I get out of that is that I really just sink down into a wonderful, peaceful place. And they'll be doing different things, they'll ask me what are your symptoms, what's your dream states like, and if I'm having more intestinal problems or whatever. And they treat me for different things, sometimes I think that it addresses the specific thing they're trying to aim for, but I don't always think that. But I always get very relaxed. It quiets my mind, which is probably my biggest enemy, my mind tends to race, pick fights with people. I kind of slip into that negative stuff a lot. So, in that way, the acupuncture is really helpful (Interview, March 10, 1995).

Tom portrays the acupuncture treatments as effective for helping him deal with the stress of daily life:

Um, acupuncture is a very interesting thing. An overview of how it makes me feel is I guess I look at it as kind of smoothing out the wrinkles, it really calms me. It makes me feel more together cause there are times when there's either some much going on physically doing stuff or so much going on mentally um, lots of worries and doing too much and trying to cram things in, and running around and all that and it just kind of brings all that down and settles it. And I find that I need to do that, it would be good to do that, or not ever get to that point, but it would be good to be able to do that very regularly, daily, on a daily basis through relaxation or whatever. But not doing that just having a weekly acupuncture performed is very important to maintain, bringing you back to sanity (Interview, March 10, 1995).

The clients at CMHC draw from the language of both Western and alternative therapies to explain the affects and the effectiveness of treatments. Rather than being limited by the language of either, they incorporate both to explain their treatment experiences. Through this process they develop explanations of what these alternative treatments do for their health which includes but is not limited to the language of Western science.

Through seeking out options the men at CMHC are both treating illness and strengthening their bodies. As mentioned before, the different perspectives of Western and alternative therapies provide different pictures of health. The emphasis of Western medicine is on the disease within the body. For the men at CMHC Western medicine is seen and used to prevent against and fight specific infections. While alternative therapies, like those at CMHC, emphasize

supporting the body and returning the balance disturbed by the invading disease.

At CMHC alternative therapies are not meant to "cure" AIDS but instead strengthen the immune system and bring the body into balance. The effect of this shift in perspective, though not directly articulated by the clients was apparent to the outsider within this setting. The majority of the men who are clients at CMHC act and seem healthy. In their physical presence they challenge the stigma of AIDS by staying strong, relaxed, and healthy.

Doing something through seeking out health care options contributes to the development of strategies by the individual for living with HIV or AIDS. Rather than allowing themselves to be defined and controlled by this diagnosis, they fight back by incorporating a variety of treatments which support both their physical wellness and their image as healthy individuals. The influence of alternative therapies, beyond the physical reduction of symptoms and stress, gives these men strategies for staying and a language of being healthy. To paraphrase Jack, from a health standpoint anything that makes you relax and alleviates stress and gives you those good feelings, comfort, and safety has got to be good for your immune system (Interview, March 10, 1995).

But it is not the treatments alone which contribute to this redefinition of what it means to be sick. CMHC plays

another role in this process by providing an actual space where these new ideas of health and wellness can be played out. In the physical and social construction of CMHC is a deliberate attempt to create an alternative perspective of being well. Although this perspective provides a base for clients to construct different images of the meaning of health, there is also the important influence of the social relations between clients and practitioners and among the clients themselves. How these social relations are enacted and played out within the comfortable space of CMHC points to the need to explore how these men, who are defined by dominant society as sick, actively seek to develop the knowledge and physical wellness to redefine themselves as living healthy lives. This is focus of the next chapter.



## CHAPTER 5

### CREATING A COMFORTABLE PLACE FOR REDEFINING THE MEANING OF HEALTH

For many of the men who visit the clinic, CMHC plays an important role in their learning to live with HIV or AIDS. This is a place where the clients are given the space to redefine the meaning of health and wellness. The men<sup>12</sup> of CMHC are seen as more than clients seeking services, they are also considered members of this organization. As members of CMHC they are encouraged to participate in the day-to-day activities of running the organization as well as being encouraged to participate in governmental activities as members of the Board of Executives.

The inclusion of clients into the organizational activities of the clinic is one of the intentional ways that the leadership of CMHC seeks to make it a comfortable place for clients. To explore the idea of a comfortable place for redefining the meaning of health and wellness I consider three broad aspects of the clinic itself which contribute to

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<sup>12</sup>According to the demographic data collected as part of this research project, six percent of CMHC's client base is women. During the project the women came to the clinic inconsistently and did not participate in clinic life. For these reasons I was not able to interview any of the women who made up the six percent.

this process. One is the intentional creation of an alternative, therapeutic, relaxing atmosphere. Second is how client-practitioner interactions provide a language for understanding health and illness and the importance of therapeutic touch. Finally, how client involvement within CMHC with other clients and as workers for the clinic influences the meaning of health and wellness for these people living with HIV and AIDS.

As described in an earlier chapter, CMHC is a different kind of clinic. The music, incense, candles, and soft lighting in the treatment rooms while meant perhaps to enhance the therapeutic qualities of the treatments also contribute to the relaxing atmosphere of the clinic overall. Even commonly expected structural aspects associated with clinics, closed doors delineating a separation of clinic activities or the white smocks of physicians, are not part of CMHC. The atmosphere appears so nonclinic-like that the addition of a receptionist's window, shortly after my research began there, seemed extremely out of place. So much so that not until I interviewed the executive director did I ever here it referred to as a "window" rather than just a hole in the wall. It was at this meeting that I also found out that the reason for the window and a new paint job was to make CMHC appear more like a clinic (Field Notes, February 12, 1995).

I assumed the results of such a structured addition to

this alternative clinic would change the friendly, chit-chatty social relations of the clinic. Once again I was surprised as I watched long-time clients virtually ignore this barrier, reaching through to answer the phone, grab a pen, or lean over to read the appointment book. Over the course of my research the window became a measure of familiarity of a client in their social interactions with the practitioners and with other clients. As new clients became more comfortable interacting within CMHC they to would breach the barrier of the window.

The intentional creation of the atmosphere of CMHC contributes to the creation of a comfortable space for clients to redefine their meanings of health and wellness. For some clients, like Mack, the atmosphere of CMHC is seen as part of the treatment process:

Prior to my leaving the clinic I had gotten so busy on the days that I was there, that I actually did forget to make my own appointments. So I hadn't had treatments in quite a while. And just being there was almost as good, as far as being a treatment, as having a treatment itself. It was good enough therapy, that my stress levels had dropped and everything (Interview, March 6, 1995).

The therapeutic affects of the atmosphere of the clinic also plays out in the interactions between clients and practitioners. Much is done by practitioners in their everyday routines to make CMHC a different kind of clinic. Trained in Traditional Chinese medicine, the practitioners provide a perspective on illness and health which is different than Western medicine. Kaptchuk provides a

comparison of Western and Chinese understanding of illness which helps me understand and explain how health is conceived at CMHC:

To Western medicine, understanding an illness means uncovering a distinct entity that is separate from the patient's being; to Chinese medicine, understanding means perceiving the relationships between all of the patient's signs and symptoms...The Chinese method is thus holistic, based on the idea that no single part can be understood except in relation to the whole. A symptom, therefore, is not traced back to the cause, but is looked at as part of the totality. If a person has a symptom, Chinese medicine wants to know how the symptom fits into the patient's entire bodily pattern (1983, 6-7).

From the perspective of many of the clients at CMHC this different understanding of illness manifests in the interactions with practitioners which clients define as different than those they have experienced in other health care settings. Many of the descriptions clients gave of practitioner interactions may sound familiar to similar types of interactions with Western medical professionals. However, the fact that many provided these descriptions as distinctively different reveals how positive their experiences at CMHC are seen as being. Jack, for example, characterized his interactions with practitioners at CMHC as making him feel comfortable, something which he did not feel when dealing with the conventional health care system:

I guess I would just have to compare it to typically what you get at most Western medical doctor meetings...Most of the time you get this feeling like everyone's in a hurry and they really don't have time to answer questions and just do what I tell you to do and get off my case. And here I feel like people listen to what you say. And every session begins with, What's

going on with you? Even something as simple as, the touch, to have your pulse taken is a real comforting kind of thing (Interview, March 10, 1995).

Weitz, (1990) contends that many of the negative feelings clients experience in interactions with health care workers is linked to the perceived stigma of AIDS. Among practitioners at CMHC efforts are taken to remove this stigma. One barrier to reducing the stigma of HIV and AIDS is the fear of contamination. But at CMHC, this barrier is broken down with the use of touch in treatment.

It is policy of CMHC that practitioners, especially massage therapists, are not to wear latex gloves when treating clients. This policy was played out when a new therapist began donating his time at CMHC. Shortly after he started working, a discussion occurred between a client and another practitioner about this new therapist who was wearing latex gloves when giving massages. The client explained that he had "had massages before but had never had one when the therapist wore gloves." The practitioner queried if it had occurred at CMHC and the client responded that he did not want to get anyone in trouble. But the practitioner was emphatic that this was definitely not the policy of the clinic and that it would not happen again. Then the client explained why this issue was so important:

It's just that the touch is the most important part of the massage and that barrier reduces the effectiveness of the treatment (Field Notes, February 13, 1995).

Eliminating the stigma of AIDS at the clinic requires

the removal of physical barriers linked to the perception of contamination like latex gloves. To remove the physical barriers requires the removal of the psychological and social barriers which are often raised when people are sick. Although caution is carefully practiced by practitioners, people who have, as one practitioner put it, a problem with dealing with people impacted by HIV or AIDS, are asked to leave CMHC.

With its focus of treatment on the strengthening or supporting the immune system, practitioners structure their diagnosis on the human body as a whole. From the perspective of many of the clients this is interpreted as emphasizing the person instead of the disease. For many clients, like Jeff, this perspective on treatment provides a feeling of normalcy:

I guess it was the first place I'd been, where it was sort of dismissed. It wasn't this like, "You have HIV!", and we have to do something. It was like, "oh, yeah, ok, lay down." And it was just like this really normal thing. And I guess after feeling so abnormal, (pause) there's a feeling here about just being however you want to be at that time and there's no, (pause) I never feel like I'm being judged about anything (Interview, April 4, 1995).

But clients come to CMHC for more than just alternative therapies. In Chicago, gay middle-class men with HIV or AIDS have several places they could chose if they were interested in alternative therapies. In the same building where CMHC is located there is another larger, more diversified alternative treatment clinic. This clinic

provides clients with access to a wide variety of alternative therapies including acupuncture, massage therapy, and herbal therapies. Although some of CMHC's clients utilize both clinics, there are also recognized differences between these two places.

One of the main differences relates to the atmosphere of the two clinics. During a conversation, Mike, a CMHC regular, characterized the differences between CMHC and another alternative health clinic. He sees CMHC as a "family oriented" place which he feels a part of. He describes the other clinic as having a nice space but he prefers the "homey" feeling he experiences at CMHC. Jeff also provided a similar comparison between the two clinics drawing from discussions he has had with other clients:

[L]ike somebody had said, "Oh have you seen [the other clinic's] new office?" And I said, "No, I haven't been down there." And somebody said, "It's really nice, but it's like a doctors office." And it's run, very, like a machine, it's very efficient. And here, good Lord, we're a mess half of the time, but it works, it runs and I think people are as comfortable as they can be. I get sort of a feeling of community here, as opposed to a place where I go for a treatment (Interview, April 4, 1995).

It seems that for many of the clients who visit CMHC the social aspects of the clinic play an important role. Although the atmosphere and their relationships with practitioners combine to create an open therapeutic environment for redefining the meaning of health it is through the social interactions among clients that provides them an opportunity to practice these new meanings as they

redefine their lives living with HIV or AIDS.

Through these interactions clients are able to explore living with HIV or AIDS without the fear of being stigmatized for either the disease or their sexual identity. Mike's use of the term 'family-oriented' reveals that for many clients, part of CMHC's attraction is that it is an openly gay friendly environment. Within CMHC being gay and being HIV positive is seen as common, if not normal. As Jeff explains this commonality makes talking about personal issues easier:

There is something very comfortable about even discussing your personal life, because everybody's in that boat. I've had wonderful conversations with clients about, "Will you date a negative guy? Or are you only going to date positive guys now. If you found a negative guy who didn't care would you still be comfortable enough?"...They face all these issues, and its done in such a way that its kind of, you know you never talk to anyone for a real long time because they're waiting to go into the treatment room or whatever, but you pick up so much from all around here (Interview, April 4, 1995).

The importance of having a positive place for exploring identity as a person with HIV or AIDS, is enhanced for many clients by the gay friendly environment. Although other clinics provide a backdrop of being gay friendly, CMHC also provides the atmosphere of a living room where these discussions seem commonplace. CMHC is like a stage where the men try on the new identities they are constructing. Identities which challenge the stigma of AIDS. They use their interaction within CMHC to develop a new perception on health that emphasizes strengthening the body along with



fighting the disease.

Some clients also challenge notions of being sick by participating in the organizational activities of CMHC. The original organization of CMHC as a donation-only clinic provided many opportunities for client involvement. Ryan and Shattuck recall the overwhelming participation of clients in providing both material and physical donations in the early days of their alternative health project:

They worked as receptionists, brought furniture and appliances, kept us in supplies, wrote newspaper articles, washed sheets, and even learn to help with simple treatment procedures like the application of moxa (a Chinese herb which is burned near acupuncture points to provide therapeutic effect via gentle heat) (1994, 6).

Clients continue to be involved in the organizational activities of CMHC. During the time of the research clients participated as board members, desk workers, washing sheets, and coordinating fund raising activities. For many this participation is seen as beneficial to their overall health and well-being. Some clients, like Tom, recognize their involvement with CMHC as a part of their therapeutic strategies:

I'm here almost every day except for the days when I really feel too crummy to drag myself over. And I find that no matter how crummy and depressed I feel at home usually when I'm here I'm up, at least somewhat more than I was at home and [a practitioner] commented to me, "You're always so up and cheerful and have a smile." And I thought, oh boy that's not me, (laughs) that's not how I know I really am all the time. But being here makes a big difference in my life...After Paul died I didn't recognize it for, oh, about a year, but I was in this constant low level state of depression, that I recognized as just sadness over his passing, and being alone, and all of that. But it was really depression,

and it was affecting my whole life. And getting involved here has kind of turned that around. This has given me a purpose to be alive (Interview, March 10, 1995).

While for other clients, involvement with CMHC provides a needed break from dealing with the outside world. As Jeff, who holds down a full-time job explains CMHC is a place where he feels that people are genuinely concerned about him:

[A]ctually, this is the place [CMHC] I feel the most supported. And the most, that I can just be myself. There is a tremendous diversity among the clientele, but there is a commonality. Its like no matter what happens during the week, I know I can come here on [my] night and it will be ok. I don't know if its as much the treatments as what I get from the people here (Interview, April 4, 1995).

The opportunities for involvement which CMHC provides have for many of the clients a normalizing effect. By being involved they become a part of a community organization that needs them and that provides them with an atmosphere that is supportive and inclusive. Through interactions with practitioners many clients gain both a new understanding of health and illness and experiences of therapeutic touch that reduce the feelings of stigma. These aspects of CMHC provide the knowledge for redefining the meaning of health but it is through the social interactions between clients that this knowledge is practiced.

The comfortable space of CMHC allows clients to negotiate their new knowledge about health into the actions of living with HIV and AIDS. It is one place where the meaning of health considers strengthening the body as

equally important as fighting the disease. Where redefining health challenges the stigma and the image of AIDS, creating a new picture of health.

## CHAPTER 6

### CONCLUSION

Through exploring the lives of the men who are clients at CMHC it becomes apparent that the ideas of health and illness which seem so straight forward are not always so clear. For these men, facing life with the diagnosis of HIV or AIDS spurs them to challenge these taken for granted notions. The process they undertake leads them to expand their treatment options to include both Western medicine and alternative therapies. By seeking out these options they are introduced to different knowledge and perspectives on health and illness.

Western medicine has as its focus the fighting of disease within the body, while alternative therapies emphasize strengthening the body and returning the balance the invading disease disturbs. Drawing on these experiences with different health systems, many of the men at CMHC begin to develop new meanings around the notions of health and illness. Through having the opportunity to negotiate these new meanings within the comfortable space of CMHC, these men are also able to challenge the stigma of HIV and AIDS by their physical health and positive outlook on the future.

Having access to alternative therapies however, does

not mean that people will engage in constructing new meanings of health. By combining Western medicine and alternative therapies individuals with HIV or AIDS expand their treatment options. This expansion is likely driven by the experiences similar to those which drew many of the clients from CMHC into the process of doing something. But for the clients at CMHC bringing alternative therapies into their overall health care strategies led them to explore new meanings of sickness and health.

There are also a few clients within CMHC who use acupuncture, massage, and herbal therapy in a similar fashion to how they use Western medicine. For them, treatments are treatments. They may change their diet, get more exercise, and give up alcohol as a reaction to their diagnosis, but they do this because experts recommend it. Similarly, the clients involved in constructing new knowledge and meanings of health, recognize the advice of experts, however the adjustments they make in their lifestyles and routines, becomes part of their process of redefining the meaning of health which influences how they understand living with HIV and AIDS. The difference between the groups is that the latter takes the knowledge of experts and recombines it, using it to support new ideas of health.

This thesis has shown how these men draw on the knowledge and perspective of Western science and alternative therapies, specifically those of Chinese medicine in order

to understand and explain their treatment regimen by positioning themselves as the center. The majority of the clients at CMHC see themselves at the center of the choices they make about treatments. Rather than relying on the experts of Western medicine who make their recommendations based on the diagnosis of HIV and AIDS, the people discussed in this research use the perspective of alternative therapies to emphasize supporting the whole body, the person.

The role CMHC plays in this person-centered knowledge construction is to provide an atmosphere and practitioner-client interactions that support the identity of the person over the disease. By intentionally removing the physical and psychological barriers of stigma the staff of CMHC creates a space where being gay and being HIV positive are normal. Not because the clinic is filled with references to either, but because of the matter of fact way these issues enter into conversations and discussions.

The comfortable space of CMHC allows clients to negotiate their new knowledge about health into the actions of living with HIV and AIDS. It is one place where the meaning of health considers strengthening the body as equally important as fighting the disease. Where redefining meaning challenges the stigma and the image of AIDS, creating a new picture of health.

## APPENDIX A

PRELIMINARY SUMMARY OF FINDINGS DRAWN FROM THE TREATMENT  
EFFECTIVENESS SURVEY, FEBRUARY 1995**Demographic data**Sex

Male 93.75%  
Female 6.25%

Relationship status

Single 56.25%  
Relationship 34.37%  
Married 6.25%  
Divorced 3.13%  
Widow 0.00%

Race or Ethnicity

African-American 6.25%  
Caucasian 87.50%  
Hispanic 3.13%

Education

Some College 18.75%  
Associates 6.25%  
Bachelors 37.50%  
Graduate 37.50%

Yearly Income

> \$15,000 12.50%  
\$15,000 to \$25,000 9.38%  
\$25,000 to 35,000 34.38%  
\$35,000 to \$50,000 15.63%  
< \$50,000 28.13%

Sexual Orientation

Heterosexual 6.25%  
Homosexual 87.50%  
Bisexual 6.25%

HIV Positive

Yes 93.75%  
No 6.25%

Path of Infection

Sexual Activity 93.75%  
Blood transfusion 3.13%  
IV Drug use 3.13%

**Information on contact with  
CMHC**How did you find out about  
CMHC?

Friends 46.88%  
Physician 6.25%  
Other 25.00%  
Media 31.25%  
Gay Chicago 40.00%  
Windy City Times 10.00%  
TPA 10.00%  
Title not listed 40.00%

Frequency of Visits

Once a week 90.63%  
Twice a week 3.13%  
Twice a month 0.00%  
Three times a month 3.13%  
Other 3.13%

Purpose of visit(select all  
appropriate)

Acupuncture 96.88%  
Work 18.75%  
Lecture or meetings 3.13%  
Massage 56.25%  
Pick up Herbs 68.75%  
Other purpose 3.13%

Donation Made

Time 21.88%  
Financial 71.88%  
Material 21.88%

Scholarship 9.38%

**QUESTIONS CONCERNING THE  
TREATMENT PROCESS AT  
CMHC (CLIENT-MEMBER DEFINED  
ANSWERS)**

Relationship with  
practitioner

Excellent	9	28.13%
Very Good	16	50.00%
Good	7	3.13%

Openness about physical  
condition with practitioner

Totally Open	12	37.50%
Very Open	10	31.25%
Open	10	31.25%

Openness about personal  
issues with practitioner

Totally Open	8	25.00%
Very Open	10	31.25%
Open	10	31.25%
Not Open	3	9.38%

Asking questions about  
treatments

Yes	25	78.13%
No	5	15.63%
Sometimes	2	6.25%

Treatments found most  
effective

Acupuncture	30	93.75%
Herbs	13	40.63%
Massage	11	34.38%
Moxibustion	2	6.25%

How treatments make client-  
members feel

Addresses Symptoms	7	21.88%
Increases Energy	8	25.00%

Gives Relaxation	16	50.00%
Sense of Doing	10	31.25%

Involved with CMHC beyond  
receiving treatments

Yes	10	31.25%
No	21	65.63%
Other	1	3.13%



## APPENDIX B

## CMHC TREATMENT EFFECTIVENESS SURVEY

Thank you for participating in this survey. The purpose of this survey is to evaluate the effectiveness of treatments and treatment process of CMHC. **ALL SURVEYS ARE ANONYMOUS AND ALL ANSWERS WILL BE KEPT COMPLETELY CONFIDENTIAL.**

Please return completed questionnaires to the CMHC office by **December 23, 1994**. To assure anonymity there is an envelope included with the questionnaire. Please put the completed questionnaire into the envelope and seal the envelope before dropping it off at CMHC.

**Section A: This section of the questionnaire asks about individuals receiving treatments at CMHC. Some of the questions are personal in nature, but the surveys themselves are completely confidential. Please answer these questions as honestly as you can.**

A1. Please fill in today's date. \_\_\_\_\_

A2. Age: \_\_\_\_\_ years      A3. Sex: \_\_\_\_\_ male \_\_\_\_\_ female

A4a. What is your current relationship status? (Please check one.)

\_\_\_\_\_ single      \_\_\_\_\_ committed non-married relationship  
\_\_\_\_\_ widowed      \_\_\_\_\_ married      \_\_\_\_\_ divorced

A4b. If you are currently in any type of committed relationship, how long have you been together? \_\_\_\_\_

A5. Race/ethnicity: (Please check one.)

\_\_\_\_\_ African-American  
\_\_\_\_\_ Caucasian(ethnic identity \_\_\_\_\_)  
\_\_\_\_\_ Hispanic  
\_\_\_\_\_ Asian  
\_\_\_\_\_ Native American  
\_\_\_\_\_ Pacific Islander  
\_\_\_\_\_ Other

A6. What is the highest level of formal education that you have achieved? (Please check one.)

\_\_\_\_\_ eighth grade or less  
\_\_\_\_\_ some high school  
\_\_\_\_\_ high school diploma  
\_\_\_\_\_ some college  
\_\_\_\_\_ Associate degree  
\_\_\_\_\_ Bachelor's degree

\_\_\_\_\_ Graduate or professional degree

**The following questions are more personal in nature. Please answer them as openly and honestly as you can.**

A7. How would you describe your sexual orientation? (Please check one.)

\_\_\_\_\_ Heterosexual (sexual involvement with someone of the opposite sex)

\_\_\_\_\_ Homosexual (gay or lesbian)

\_\_\_\_\_ Bisexual (sexual involvement with both men and women)

\_\_\_\_\_ Asexual (not sexual)

A8a. Are you HIV positive? \_\_\_\_\_ yes \_\_\_\_\_ no

A8b. If yes, when did you learn you were HIV positive? \_\_\_\_\_

A8c. If yes, which of the following would you most likely identify as the way you contracted HIV? (If unsure, please check all possible answers.)

\_\_\_\_\_ Sexual activity

\_\_\_\_\_ Blood transfusion

\_\_\_\_\_ Intravenous drug use

A9. Please answer the question that best describes your present employment situation.

a. If you are employed, what is your occupation?

\_\_\_\_\_

b. If unemployed, what was your previous occupation?

\_\_\_\_\_

A9c. If unemployed, is your unemployment HIV or AIDS related? \_\_\_\_\_ yes \_\_\_\_\_ no

A9d. If yes, please explain how? \_\_\_\_\_

\_\_\_\_\_

A10. What is your annual income? (Please check one.)

\_\_\_\_\_ Less than \$15,000

\_\_\_\_\_ between \$15,000 and \$25,000

\_\_\_\_\_ between \$25,000 and \$35,000

\_\_\_\_\_ between \$35,000 and \$50,000

\_\_\_\_\_ greater than \$50,000

**Section B: The following questions concern your relationship with CMHC. Please answer each question as completely as you can.**

B1. Approximately when did you start treatments at CMHC?  
Date \_\_\_\_\_

- B2. How did you find out about CMHC?
- Through friend/s \_\_\_\_\_
  - Through physician \_\_\_\_\_
  - Through newspaper \_\_\_\_\_ (title \_\_\_\_\_)
  - Through magazine \_\_\_\_\_ (title \_\_\_\_\_)
  - Through other media \_\_\_\_\_ What was it? \_\_\_\_\_
  - Other \_\_\_\_\_ (explain \_\_\_\_\_)
- B3. How often do you come to CMHC?
- Once a week \_\_\_\_\_
- Two times a week \_\_\_\_\_
- Twice a month \_\_\_\_\_
- Three times a month \_\_\_\_\_
- Other \_\_\_\_\_ (please explain \_\_\_\_\_)
- B4. What is the purpose of these visits? (Check all that apply)
- \_\_\_\_\_ Acupuncture
- \_\_\_\_\_ Donate work hours
- \_\_\_\_\_ Lectures or meetings
- \_\_\_\_\_ Massage
- \_\_\_\_\_ Pick up herbs
- \_\_\_\_\_ Other \_\_\_\_\_
- B5. How would you characterize your:
- |                     |      |      |      |           |
|---------------------|------|------|------|-----------|
| energy level        | poor | fair | good | excellent |
| activity level      | poor | fair | good | excellent |
| physical condition  | poor | fair | good | excellent |
| sense of well being | poor | fair | good | excellent |
| symptomatic areas   | poor | fair | good | excellent |
- B6. What type of donation do you usually make to CMHC?  
(Check all that apply.)
- \_\_\_\_\_ Time/Work
- \_\_\_\_\_ Financial
- \_\_\_\_\_ Material
- \_\_\_\_\_ Scholarship
- \_\_\_\_\_ Other (explain \_\_\_\_\_)

**Section C: The following questions are about the treatment process at CMHC. Please answer them as completely as possible. If you need more room to answer please use the back of the questionnaire.**

C1. How would you describe your relationship with the practitioner?

C2. How open are you about your physical condition with the practitioners?

C3.How open are you about other personal issues with the practitioners?

C4.Do you ask questions about the treatments?

C5.Which of the treatments do you find most effective for you?

C6.How do the treatments make you feel? (Physically, mentally, etc...)

C7.Are there other ways, beyond receiving treatments, that you are involved with CMHC?

C8.Do you have any recommendations to help CMHC better service you?

## APPENDIX C

## MEMBER INTERVIEW FORM

Date: \_\_\_\_\_ Time: \_\_\_\_\_  
Code: \_\_\_\_\_  
Place: \_\_\_\_\_

INTRODUCTION

Since September of 1994 I have been doing research with CMHC trying to understand the effectiveness of treatments. We wanted to know which treatments were found most effective by members and in turn how treatments affected members quality of life.

Surveys, handed out last November, gave us a broad idea about which treatments members found most effective but we want to expand on this broad knowledge. To accomplish this a series of interviews are being conducted to develop in-depth understanding of how the treatments effect you and how what happens at CMHC affects your quality of life.

CMHC will use the information gathered through this interview to help them better understand organizational processes to be responsive to the needs of their members. With your permission the interview will be tape recorded. To protect your identity the tapes and notes taken during the interview will be transcribed with all identifying information changed. All interviewees will remain anonymous.

Having heard the above statements, do you agree to be interviewed? (YES, NO)

Do you agree to have the interview tape recorded?  
(YES, NO)

INTERVIEW TOPICS

## PERSONAL HISTORY

Age                      Education  
Race                     Occupation  
What is your history with HIV?  
How long have you been HIV positive?  
What did you do when you found out?

## TREATMENT

Treatment regimen  
What types of treatment are you involved in?

How much time do you spend doing treatments?  
 Where does CMHC fit in this regimen?  
 How do you think the treatments interact? Compare  
 them.  
 Within your body?  
 Within society?

#### Western and Alternative therapies

##### Western medicine

What is your involvement with Western  
 medicine?  
 What kind of medical treatments do you use  
 since being diagnosed HIV+?  
 Does your doctor know about the rest of your  
 use of alternative therapies? Explain?  
 How does the Western medicine affect you?

##### Alternative therapies

When did you decide to use alternative  
 therapies?  
 Were you involved before you knew you were  
 HIV positive?  
 How did interactions with Western medicine  
 influence your use of alternatives?  
 Explain what different treatments you use.  
 How does each treatment affect you?  
 Which treatments do find most  
 beneficial?

#### INVOLVEMENT WITH CMHC

What brought you to CMHC?  
 Networks, needs, interests  
 What did you think when you came here? What was  
 your impression?  
 How has it changed?  
 How long have you been involved?  
 How are you involved (connected) with CMHC?  
 What sort of changes have you seen CMHC go through?  
 What would you do differently with the  
 organization?  
 How do you see CMHC in the future?

Are there some other issues that we haven't talked  
 about yet that you would like to discuss?

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## VITA

Lorraine Lynn graduated from Pennsylvania State University-Harrisburg in 1991 with a Bachelor of Social Science degree. She worked as a secondary school teacher and coordinated a summer program for urban middle school students for Cities in Schools of Dauphin County in Harrisburg, Pennsylvania. During her first two years at Loyola University Chicago, Lorraine was a research assistant for the Policy Research Action Group (PRAG) where she gained valuable experience working on collaborative research projects between several community-based organizations and PRAG. She has presented the research from the Chinese Medicine HIV Center at two conferences and a version of this research was published in the health care journal, Alternative and Complimentary Therapies.

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The final copies have been examined by the director of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the committee with reference to content and form.

The thesis is, therefore, accepted in partial fulfillment of the requirements for the degree of Masters of Arts.

4/3/96

Date



Director's Signature